

## Rights, interests and expectations: Indigenous perspectives on unrestricted access to genomic data

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**Abstract** | Addressing Indigenous rights and interests in genetic resources has become increasingly challenging in an open science environment that promotes unrestricted access to genomic data. Although Indigenous experiences with genetic research have been shaped by a series of negative interactions, there is increasing recognition that equitable benefits can only be realized through greater participation of Indigenous communities. Issues of trust, accountability and equity underpin Indigenous critiques of genetic research and the sharing of genomic data. This Perspectives article highlights identified issues for Indigenous communities around the sharing of genomic data and suggests principles and actions that genomic researchers can adopt to recognize community rights and interests in data.

Advances in genomic analysis and decreasing costs for genome sequencing have given rise to a proliferation of projects to sequence people, plants, animals and environments<sup>1</sup>. Similar advances in data science provide computing and analytical power to derive greater insights from these projects<sup>1</sup>. Aggregating data sets and facilitating reuse are logical paths towards deriving more value from initial investments. This narrative underpins the open science movement, which argues that supporting open data initiatives produces more research that creates greater societal benefits<sup>2</sup>. These ideas reflect the interests of the scientific community in data resources generated about people and their environments and establish the basis for such claims<sup>2,3</sup>.

Alongside this call for data openness is a growing acknowledgement that not all members of society have received

equitable or fair treatment through these ambitions. Indeed, the relative distribution of risks and benefits tends to fall unevenly in relation to Indigenous communities<sup>4</sup>, which carry substantial risk but see few of the benefits of genomic research<sup>5</sup>. Indigenous Peoples form a meta category covering the estimated 370 million people living across the inhabited continents of the planet<sup>6</sup>. The lifeworlds of those peoples are hugely variable and their cultural diversity often parallels unique genetic origins<sup>7</sup>. We focus on Indigenous Peoples in colonized, high-income countries, in part because these Indigenous communities have often had a greater opportunity to voice concerns, and also because high-income countries are primarily responsible for generating genomic data.

Numerous research projects, genomic or otherwise, exhibit enduring negative effects on Indigenous Peoples<sup>8</sup>, minority

populations<sup>9,10</sup> or socially disadvantaged groups<sup>11,12</sup> owing to under-representation, lack of informed consent, lack of consultation, misinterpretation and/or misuse of samples and data<sup>1,8,13,14</sup>. A recent example is the *All of Us* project — a historic research effort sponsored by the US National Institutes of Health (NIH) aiming to gather genetic, environmental and lifestyle data from over 1 million US residents. As this project has progressed, clear failures in tribal consultation have arisen, to the extent that the National Congress of American Indians passed Resolution ABQ-19-061 calling on the NIH to “immediately develop clear processes and guidelines that ask individual sovereign tribal nations to provide prior consent before collecting data and specimens from their tribal members, and provide tribal nations oversight of any data or biospecimens that are associated with or identified to be from a citizen of their tribal nation”<sup>15</sup>.

In this article, we outline perspectives from Indigenous scientists and communities defining responsible access to genomic data. We explore the rights and interests that Indigenous communities might have in genomic data and propose several principles for sharing genomic data derived from Indigenous communities.

### Trust, accountability and equity

Calls for unrestricted and open access to genomic data have not yet fully addressed the importance of maintaining public trust, especially across diverse Indigenous communities. There are numerous studies citing the concerns of the general public about trust in research, biobanking and data governance<sup>9,16,17</sup>. Similarly, diversity and inclusion are being discussed in relation to genomic research to address issues of justice, equity and scientific rigour<sup>10,18–21</sup>. Despite an increasing awareness within the scientific community of the value of improving diversity and inclusion in genomic research, there remains an aversion to addressing inherent exclusions that inform and are perpetuated through blanket ideals of openness. As Bentley et al. state in the context of genomic research in Africa, “Public trust, oversight, and long-lasting relationships with communities who participate in genomic research are required

to advance both data sharing and diversity and inclusion — two major components of genomic research that must advance symbiotically for genomic research to benefit all<sup>19</sup>.

Mistrust is particularly concerning for Indigenous Peoples and minorities<sup>1,8,20–26</sup>. Of essential importance, genomic data are commonly seen by Indigenous communities as more sensitive than other types of health data<sup>24,27</sup>, particularly with regard to genealogy and ancestry research that can influence traditionally held beliefs, cultural histories and identity claims affecting rights to land and other resources<sup>27,28</sup>. Whereas international and national ethical guidelines expect researchers to consult with Indigenous communities in the development of research projects<sup>8</sup>, some Indigenous communities have expressed a lack of confidence in the ability of institutional ethics committees to ensure appropriate consultation<sup>8,13,14</sup> or to address unethical conduct<sup>24,29–31</sup>. Indigenous Peoples have also expressed concerns in debates at international fora on free prior and informed consent as well as access and benefit sharing<sup>32–36</sup>. Within international law, Article 31 of the United Nations Declaration on the Rights of Indigenous Peoples states that “Indigenous peoples have the right to maintain, control, protect and develop their cultural heritage, traditional knowledge and traditional cultural expressions, [...] including human and genetic resources<sup>36</sup>”.

Indigenous Peoples’ interests in genomic resources are engaged across the United Nations system, including the Permanent Forum on Indigenous Issues (UNPFII), the World Intellectual Property Organization (WIPO) and the Convention on Biological Diversity (CBD)<sup>13,37,38</sup>, especially through the Nagoya Protocol. Diverse Indigenous voices active within these contexts consistently express concerns about appropriate consultation, clear guidelines for future use and control of genomic data, and unanticipated consequences from accidental privacy disclosures<sup>39</sup>. Increasing claims by Indigenous representatives to genomic data and resources<sup>1,8,13,14,40,41</sup> reflect both the interdependent relationship between Indigenous communities and their environments and the limited capacity for existing instruments at international and national levels to protect their rights and interests<sup>27,42</sup>. As with sovereign rights to lands and territories<sup>36</sup>, genetic resources and genomic data are important resources within Indigenous communities to which they hold rights, relationships, responsibilities and obligations now and into the future<sup>24,43,44</sup>.

The use of ethics review committees as sole arbiters of appropriate access to and use of Indigenous samples and/or genomic data<sup>3</sup> is inconsistent with Indigenous rights and interests. Institutional ethics committees largely lack Indigenous representation, do not recognize or promote Indigenous research ethics principles and often fail to support Indigenous governance of research and data<sup>45,46</sup>. Ethics review processes are limited in their ability to deal with increasing expectations for open access and secondary use. For instance, over-reliance on current consent paradigms to address issues of future use is problematic given that neither the researcher nor the participant knows all the potential uses of the samples/data into the future<sup>47</sup>. Adopting principles of dynamic consent<sup>48</sup> — an interactive approach to re-consent that allows participants to revisit their consent choices and update them over time — or recognizing the legitimacy of Indigenous governance processes<sup>14</sup> can provide more meaningful approaches to maintaining participant trust. For example, formal agreements, such as memorandums of understanding/agreement, developed through appropriate community consultation can address collective risks and represent a form of collective consent or community approval<sup>1,8,13,14,43</sup>. This method strengthens Indigenous governance from the outset with a community, enhancing the work of institutional ethics committees. Robust consultation means that each community can decide on a case-by-case basis whether there are any cultural or commercial considerations to address and if the particular project adds value to their community.

Open access to genomic data and associated metadata runs counter to values expressed through the Indigenous data sovereignty (IDSov) movement, which advocates for greater Indigenous control of Indigenous data<sup>6,41</sup>. IDSov aims to protect collective interests and generate benefits from data by ensuring ‘data for governance’ and ‘governance of data’<sup>6,41</sup>. IDSov asserts inherent Indigenous rights and interests in genomic data, expects Indigenous participation in the governance of genomic samples/data and anticipates Indigenous communities’ involvement in research and policy that affects their lives and livelihoods<sup>8,13,43,49,50</sup>. Unrestricted open access to data effectively removes the need for ongoing consultation with Indigenous communities and, therefore, their opportunity to mitigate harms, discuss benefits or address issues of equity and autonomy<sup>8,51</sup>. The primary ethical justification for open access is the

expectation of benefit<sup>52</sup>. However, numerous subpopulations provide data that can be used against them — groups including drug users, sex workers, undocumented migrants and Indigenous nations, such as American Indian tribes. Given the compounding issues of economic marginalization, social inequalities, institutional racism and health disparities impacting most Indigenous Peoples<sup>7</sup>, enabling pathways to implementation and benefit from research is challenging<sup>53,54</sup>.

As translating genomics research into health care for general populations is a complex endeavour<sup>39,55–57</sup>, it is unsurprising that many genomics projects show no clear path to tangible benefits for Indigenous communities. Social benefit for communities might include the return of meaningful results and/or support for health promotion activities. This outcome is a key concern expressed in recent literature on access and benefit sharing<sup>8,13</sup>, Indigenous research ethics<sup>1,3</sup> and Indigenous rights<sup>41,43,48</sup>. Reducing the genomic divide<sup>43</sup> requires building better relationships with Indigenous communities through the development of new pathways for engagement, consent and governance over genomic research<sup>1,14,44,51,58,59</sup>. As Johnson et al. state, “tackling inequalities [...] is important [...] because a lack of ethnic diversity in genomic medicine substantially decreases the capacity for social benefit”<sup>52</sup>.

Public funders anticipate that research will lead to public benefit and expect that opening access to data and encouraging greater data sharing will enhance public benefits. This view is reiterated by the open science movement and belies the transition of public data to private entities via commercial investment. Critical reflection upon the notion of ‘the public’ presumes a notion of inclusion and representativeness that is often at odds with Indigenous experiences within colonial contexts. The interests of ‘the public’ and those of Indigenous Peoples should not be presumed to be synonymous<sup>60</sup>. The under-representation of Indigenous communities in genomic studies<sup>18</sup> is likely to be a consequence of difficult histories with genomic research, including inadequate consultation and collaboration, lack of funding opportunities, lack of local resources and lack of infrastructure<sup>1,8,22,61</sup>. Indigenous communities want to experience direct benefits from participation and collaboration in genomic research when it draws on knowledge of their lands, species and waters<sup>8,14,62</sup>. Access to information, data and future opportunities

are important outcomes for Indigenous communities. Access to the results of research is a generally accepted outcome from consultation before and through research<sup>8,41</sup>. In addition, tribal expectations for managing access to the raw data have emerged from the IDSov movement<sup>41</sup>. Recognition of Indigenous rights to control Indigenous data and associated information resources also maintains the opportunity for benefit sharing to arise from future commercialization activities<sup>8,13,37</sup>. Alongside contemporary inequity in research processes, balancing expectations of open data access with community desires for the protection of future opportunities is a substantial challenge. From multiple community standpoints, potential benefits arising from genomic research include improved community and environmental health and well-being<sup>13,62</sup>, targeted education and training<sup>13</sup>, capacity building for Indigenous researchers<sup>1,8</sup> and partnering around entrepreneurial activities<sup>14,37,43</sup>.

### Implications for genomic research

In the context of genomic research, it is imperative that relationships between participants, communities and their biospecimens/data are maintained by researchers over time. Enhancing the participation of Indigenous communities in genomic research will require the recognition of their rights and interests in genomic data and consequently will require radical improvements in trust, equity and accountability<sup>1,8,21,44</sup>. With the increased scrutiny of claims to intellectual property rights over naturally occurring genome sequences, legitimate questions arise about other approaches that recognize stakeholder interests in genomic data. Multiple examples apply here, but, for our purposes, the Fort Lauderdale Agreement is important<sup>63</sup>. This Agreement identifies responsibilities and obligations for funders, resource producers and resource users sharing data from large-scale biological research projects. Yet this Agreement fails to acknowledge the rights or interests of Indigenous communities from which the samples or source materials originate<sup>63</sup>. In fact, the need to include information about the origins or provenance of data is not even mentioned, thus sidestepping one of the most critical concerns for Indigenous ethics in the production of data for the future.

Open access supports an intent that is different from the right to privacy and/or control of access to data. Open data initiatives create momentum towards greater access; however, initiatives like the General

Data Protection Regulations in the European Union strengthen privacy rights, including the right to be forgotten<sup>64</sup>. Thus, calls to openness in data access and sharing have to reconcile interests that have not only been historically excluded and marginalized but also address inherent tensions between ideals of openness and the realities of legislation around data privacy. From an Indigenous perspective, this means moving away from blanket calls for ‘openness for human benefit’ to more nuanced, careful and clearly articulated positions that can support open and accessible data while recognizing limitations and the possibility of restrictions. Importantly, these limitations may arise for cultural reasons and for legitimate desires to develop opportunities for commercialization that directly benefit Indigenous Peoples.

There are existing examples of restricted or controlled access to genomic data repositories. To access data from both the NIH National Center for Biotechnology Information (NCBI) database of Genotypes and Phenotypes (dbGaP) and the UK Biobank, researchers must apply to a data-access review committee, who ensure that the project is consistent with the informed consent provisions<sup>65,66</sup>. There are also examples of genomic databases in which private data sets are curated alongside public data sets. The Integrated Microbial Genomes with Microbiome Samples system holds sequence data generated by the Joint Genome Institute (JGI), which allows for both open-access interactive analysis of publicly available data sets as well as login/password access via principal investigators to private data sets for a set period of time<sup>67</sup>. The legitimacy of some requests to control access to data is accepted for specific contexts<sup>68</sup> that could be extended to Indigenous aspirations for greater control over Indigenous genomic data. Although there is a general acknowledgement that researchers and institutions will have interests in the Indigenous genomic data that they generate, it is expected that discussions with Indigenous Peoples inform how those interests translate into specific rights for all parties.

To support both data governance and pathways for researchers to access Indigenous genome sequences, existing infrastructures and technologies that support Indigenous control over Indigenous data require review. TABLE 1 identifies the key data issues for Indigenous communities and proposes actions for researchers that enhance their responsiveness towards Indigenous rights and interests in genomic data. Current frameworks in place — from international agreements to national ethics

review committees — do not address issues of trust, accountability or equity for Indigenous communities. Assumptions persist that Indigenous interests align neatly with other constructed public interests when they do not. Equity in information and data sharing cannot assume a level playing field and must account for historical power imbalances and the treatment of Indigenous Peoples as research subjects, not as research partners. However, there are ways to enhance Indigenous involvement in data governance structures and data-access processes that promote greater participation in decision-making, ensure appropriate secondary uses and maintain connections between communities and next-users of data. Transparency about the origins and provenance of genomic data, the ways in which the genomic data are accessed and used, and how benefits are generated and distributed equitably are central to maintaining a high level of integrity within the research enterprise. The issues for Indigenous communities cohere into three broad principles for the use of Indigenous genomic data to support greater diversity and inclusion of Indigenous Peoples in genomic research (FIG. 1; TABLE 1).

1. Building trust, whereby Indigenous communities decide whether their genomic data and associated metadata are publicly available or accessible on request
2. Enhancing accountability, in which the provenance of Indigenous samples and genomics data must be transparent, disclosed in publications and maintained with the data
3. Improving equity, whereby credit should be given to Indigenous communities to support future use and benefit-sharing agreements as appropriate

Below and in TABLE 1 we describe further details of these principles and our recommendations for genomics research practices going forwards.

### Promoting better research practices

Ethical standards evolve over time, either prompted by the need to address ethical implications of new technologies or developed in response to unethical behaviour. The convergence of digital and biological technologies, as well as the increasing level of data sharing between research and societal platforms, links ethical concepts from different disciplinary traditions, reaffirming social and cultural expectations for those new contexts and guiding next-generation research practice. Developing infrastructures to enhance levels

of trust, benefit sharing and accountability through greater recognition, control and transparency are necessary to increase Indigenous participation in genomic research, but how might these be addressed?

**Building trust.** Indigenous scientists have developed frameworks to guide genomic research and biobanking in their communities<sup>1,6,16,26,69–72</sup>. Enhancing levels of engagement and control are key components of creating a research environment that has integrity from an Indigenous perspective. Indigenous authors have begun to describe what this looks like, providing practical pathways for genomic researchers. Tauali'i et al. developed protocols for participation, governance and education in Hawaiian communities guided by the six principles that comprise 'G.R.E.A.T. Research' (Governance, Re-consent, Education, Accountability, Transparency, Research priorities)<sup>58</sup>. Transparency and accountability in the operational aspects of research should align

with enhanced Indigenous participation through governance and re-consent, while delivering education and research outcomes that support the community's priorities. Claw et al. identified six principles to build trust and increase inclusion of American Indian and Alaska Natives in genomic research, including understanding existing regulations, fostering collaboration, building cultural competency, improving transparency, supporting capacity and disseminating research findings<sup>1</sup>. In New Zealand, Henare et al. created a roadmap for engagement with Māori to inform a neuroendocrine tumour research programme<sup>44</sup>. The roadmap applied the principles articulated within the Te Mata Ira Guidelines for Genomic Research with Māori<sup>73</sup>. The H3Africa Initiative also created an ethical framework to guide genomic research and biobanking in Africa, which includes the core principles of African intellectual leadership, consent, community engagement, ethics review, avoidance of group harm and stigma, benefit

sharing, capacity-building, international collaboration and export of samples, feedback of individual genetic findings and good governance<sup>74</sup>. The South Australian Aboriginal Health Research Accord, developed through a series of consultations with Aboriginal Elders, organizations and community members, sets out nine principles by which Aboriginal health research (including genomic research) in South Australia should be conducted. The principles include priorities, involvement, partnership, respect, communication, reciprocity, ownership, control, and knowledge translation and exchange<sup>75</sup>.

Similarly, genome research undertaken with San involving both humans and traditional medicine plants has resulted in a range of harms for the community<sup>37,76</sup>, including, from a community perspective, the misrepresentation of the San community, a lack of respect for community leaders and disparaging inferences made in publications and the media. San leaders in South Africa responded by developing

Table 1 | Enhancing responsiveness towards Indigenous rights and interests in genomic data

Principle	Issues raised by communities	Actions for researchers
Building trust	Lack of early consultation	Engage with the appropriate entity to discuss the aims of the project, including data use and access; engage community rights-holders/stakeholders about the use of cultural knowledge, customary laws and cultural protocols
	Plans for data access and secondary uses	Define informed consent language for potential data access and secondary uses; engage with Indigenous governance processes to establish a participatory governance process and decide secondary uses; provide community education and/or multilevel consent processes
	Receiving ongoing research updates	Communicate regularly via mechanisms determined by the community to enhance transparency
	Exercising data governance	Community determines the level of data access; abide by Indigenous governance processes that support control over samples and data
Enhancing accountability	Formalizing data access and secondary use agreements	Obtain tribal/board approval and develop a memorandum of understanding; secondary use process established with potential community veto
	Protecting personal identifiers	Maintain appropriate levels of privacy; develop mechanisms to remove a participant's data from data sets (for future uses)
	Protecting community identifiers	Consultation with Indigenous communities to reduce collective harms; create a publication review process that honours Indigenous considerations regarding results (how the community wants to be named) and interpretations (reduce bias), and develop mechanisms to remove a community's data from data sets (before analysis)
	Appropriate study design	Studies should be designed to ensure equal explanatory power (statistical significance for subpopulation analyses) and produce relevant results for Indigenous communities
	Preventing misuse of data	Where expertise is available, involve Indigenous scholars and community members in data analysis and interpretation; community involvement in data governance and decisions about data access
	Improving publication standards	Recognize origin and provenance of samples, recognize community support for the study and recognize data availability and data governance processes
Improving equity	Recognizing community rights and interests	Appropriate attribution of community support within publications
	Collecting appropriate cultural metadata	Work with communities to collect relevant traditional knowledge and community interests; use labels to maintain provenance on data-sharing platforms
	Formalizing benefit-sharing agreements	Develop formal agreements for benefit sharing or process to transition from research to commercial applications
	Enhancing capacity	Collaborate with communities to build capacity and capability in the data life cycle

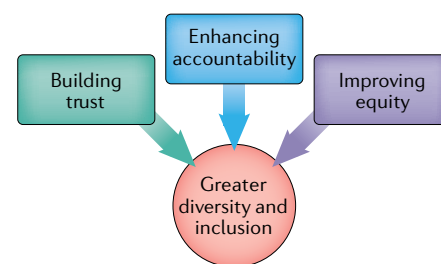


Fig. 1 | **Principles proposed to support greater Indigenous diversity and inclusion in genomic research.** Building trust emerges through recognizing Indigenous rights and interests in data. Enhancing accountability arises through maintaining transparency around the provenance of samples and data. Improving equity occurs when Indigenous communities benefit through publication, research or commercialization activities.

and this attribution is maintained as the data travel<sup>59,93</sup>. Data provided to genomic databases could be labelled in ways similar to how Traditional Knowledge Labels<sup>94</sup> are being developed by Indigenous communities for identifying provenance, origin and authority over their cultural materials held in research and cultural institutions<sup>94</sup>. As digital protocols for data, labelling can ensure that next-users are aware of approved uses and know who to contact should the need arise to explore benefit sharing. Cultural metadata also add value to the research endeavour and the creation of Indigenous fields within databases adds transparency and accountability to the research environment. The emergence of coordinating metadata databases — that is, Genomic Observatories Meta-Database (GeOMe)<sup>95</sup> and *Atlas of Living Australia* — provides opportunities to more explicitly engage with Indigenous communities, enabling the creation of new fields inclusive of Indigenous data in these systems. Although concern remains regarding misappropriation of traditional knowledge, cultural metadata could enhance existing systems if appropriately supported by Indigenous protocols and by technologies like blockchain that make data control and provenance more overt, including where relevant at the level of the individual, family and community.

The views of different Indigenous communities and individuals within those communities on the use of genomic data inevitably cover a broad spectrum of views from unrestricted open access to controlled access to no access. As Indigenous researchers and responsible scientists, we appreciate the value and importance of data availability and are not advocating for one position or another. As agencies

a San Code of Research Ethics outlining principles of respect, honesty, justice and fairness, care for the community involved and willingness to follow due process<sup>77–79</sup>. These issues continue with the recent challenges directed towards the Wellcome Trust Sanger Institute (UK) for its role in creating a commercial array product using San DNA samples without appropriate benefit-sharing agreements in place<sup>80</sup>. The heightened sensitivity to these situations reflects a general lack of trust with the genomics community and the legacy issues associated with a history of culturally inappropriate behaviour.

The Research Data Alliance International Indigenous Data Sovereignty Interest Group<sup>81</sup> developed the CARE Principles for Indigenous Data Governance. These principles identify collective benefit, authority to control, responsibility and ethics to be used alongside other data-centric principles. For example, the FAIR Data Principles for scientific data (findable, accessible, interoperable, reusable)<sup>82</sup> and other existing principles centre on improving data quality for secondary use. The CARE Principles add important elements by bringing a ‘people’- and ‘purpose’-centric approach to the use of data, promoting Indigenous rights and interests as part of the data process necessary for the creation and sharing of high-quality, equitable data<sup>83</sup>. The clear commonalities across Indigenous guidelines are an expectation of ethical engagement, the need for researchers to develop their cultural competencies, support for education and capacity building in the community, and a greater alignment between the uses of genomic data and Indigenous priorities.

**Enhancing accountability.** Indigenous Peoples have raised critical questions about the integrity of the systems governing institutionalized research enterprises<sup>8,21,84</sup>. As a result, efforts are being made to enhance the accountability of researchers and institutions to deliver culturally appropriate genomic research with Indigenous communities supported by increased Indigenous research capacity<sup>8</sup>. Indigenous aspirations for self-determination and control of Indigenous resources and Indigenous data have led to the development of community-specific research review boards, Indigenous-controlled data repositories (for example, the Indigenous Background Variant Library<sup>85</sup> and the Aotearoa Variome<sup>86</sup>) and Indigenous-controlled research infrastructures, such

as Indigenous-controlled biorepositories (for example, the South Australian Health and Medical Research Institute<sup>87</sup> and the Native BioData Consortium<sup>88</sup>). The aim of creating Indigenous data repositories is to allow Indigenous communities to directly manage access to sensitive or valuable genome sequences and associated metadata, including traditional knowledge. Benefits are more likely to arise if research data and research information are returned to communities in relevant and useable formats. This might be done in collaboration with other entities that specialize in knowledge translation or implementation<sup>54</sup>. Publishers, funders and ethics committees share interests in transparency and, therefore, should work more closely with Indigenous communities to foster accountability around better research practices<sup>89</sup>. Publishers can also contribute to improving accountability in the research system by creating standards for manuscripts to require disclosure of origin statements, disclosure of community consent statements, and data availability statements to improve transparency in relation to the provenance of genomic data and level of community support for research activities. A recent example demonstrating explicit acknowledgement of community support for sequencing an Indigenous species was included for publication in the following manner: ‘Victor Goldsmith from Ngati Porou Miere Ltd and representing the Ngati Porou tribal group (iwi) approved the use of plant material from the EC201xEC103 segregating population that was developed from crossing parental trees collected within their ancestral boundaries<sup>90</sup>. The data from this study were deposited in a New Zealand-based, controlled-access data repository developed by Genomics Aotearoa<sup>91</sup>. The justification for deposition in this repository is provided in the paper ‘Science at the intersection of cultures — Māori, Pākehā and mānuka’<sup>92</sup>.

**Improving equity.** Fair and equitable benefit sharing of genetic resources is an expectation of the Nagoya Protocol, and fairness and equity are key goals of health systems and health research. Although the Nagoya Protocol does not yet formally apply to Digital Sequence Information, low- and middle-income countries and Indigenous communities expect the value generated from genomic data to be subject to benefit-sharing arrangements. Benefit sharing might be enhanced through the use of labelling systems to ensure that the origin of samples is appropriately disclosed

become more responsive to aspirations of Indigenous communities and the science community becomes more sensitive to the concerns of Indigenous communities, the research environment has become more conducive to understanding the cultural implications of genomic research<sup>73</sup>. Based on our experiences, Indigenous rights literature and general feedback, we argue that to address the lack of diversity and inclusion in genomics we need to be more cognizant of the issues of trust, accountability and equity that pervade our scientific domain. Sharing power through enhanced engagement in research and control over data sharing will allow communities to decide whether data should be in open data environments or controlled data environments. These environments already exist, and a more nuanced approach to data sharing<sup>19</sup> is better suited for addressing Indigenous Peoples' concerns about control of data rather than attempting to convince them of the ethical legitimacy of the open data approach.

**Conclusion**

Generation of big data, including genomic data, is accelerating biological discovery and increasing the value of the knowledge economy. Opportunities for Indigenous communities to benefit in an equitable manner depend on the rights that are assigned to different participants in the research enterprise. It is vital that we do not perpetuate the continued disempowerment of Indigenous communities through the appropriation of their genetic heritage and genomic data. Although allowing unrestricted access to genomic data can enhance scientific innovation, it can alienate Indigenous communities from the research process and limit the effectiveness of access and benefit-sharing protocols. Levels of trust and accountability can rise only through the development of closer relationships between genomic researchers, on the one hand, and Indigenous communities and Indigenous genomic scientists, on the other, as well as the distribution of real benefits back to the communities themselves. The international instruments that promote benefit sharing can be realized only through continued recognition of Indigenous rights and interests, as well as a commitment to partnership and power sharing in the development of genomic research initiatives.

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#### Author contributions

R.S. researched data for the article. M.H., N.A.G., N.R.C., K.F., J.Y., J.A., P.W., L.A., A.B., M.T., T.K., R.H., B.T.A., G.S.B., P.K.D., D.C., R.S.M., I.G., N.T., D.B., M.S., A.K.R., L.L.B., R.L., D.D.-C., A.M., A.S., M.W., J.R. and S.R.C. substantially contributed to discussion of content. M.H., N.A.G., R.S. and

S.R.C. wrote the manuscript. M.H., N.A.G., N.R.C., K.F., J.Y., J.A., P.W., L.A., A.B., M.T., T.K., R.H., B.T.A., G.S.B., P.K.D., D.C., R.S.M., I.G., N.T., M.S., A.K.R., L.L.B., R.L., D.D.-C., A.M., A.S., M.W., J.R. and S.R.C. contributed to reviewing/editing the manuscript before submission.

#### Competing interests

J.Y. and K.F. are executive board members of the Native BioData Consortium biorepository (501.C.3 non-profit). The other authors declare no competing interests.

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